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No. 20
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Children with Disabilities: Medication and Health Care Patterns

In this 20th edition of the CCSD's *Disability Research Information Sheets*, we provide information from the 2001 Participation and Activity Limitation Survey of Children (PALS).[1] We focus on patterns of medication use, health services, and the coordination of care by parents/guardians.

Medication Use

Patterns of Medication Use:

According to the 2001 PALS, nearly half of all children with disabilities (47.3%) took some form of medication – both prescription and non-prescription – on a regular basis, with regular being defined as "at least once a week."[2] If we examine the patterns of medication use by looking more closely at "prescription" versus "non-prescription" medications and "daily" versus "weekly" use, we find that the most prevalent pattern among children was the daily use of prescription medication: 41.5% of children with disabilities took some form of prescription medication daily; 10% took some form of non-prescription medication on a daily basis; 14.2% took prescription drugs weekly; and 8.9% took non-prescription

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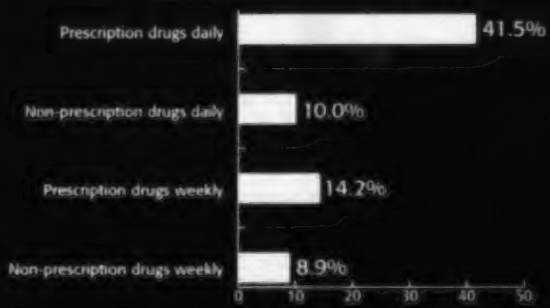
[1] The Children's PALS is a post-censal survey, that is, a survey which uses a Census question to identify the target population of persons with disabilities. It was conducted in 10 provinces, but excludes the Yukon, Northwest Territories, and Nunavut. It contains rich disability-specific information.

[2] The new screening questions on the 2001 PALS for Children seem to have captured a population of children with more severe disabilities than other screening questions used in the past (such as in the 1986 and 1991 HALS). This might be a factor in our findings around the use of medication.

drugs weekly.[3] It is important to note that these figures refer only to those who actually *used* medication; they do not include those who might have needed medication but didn't have it. Thus, these are "use rates," not "requirement rates."

Chart 1 **Basic Patterns of Medication Use, Children under age 15 with Disabilities, Canada, 2001**



Note: Some individuals take both prescription and non-prescription medication daily and weekly. These categories are not mutually exclusive.
Source: Calculations by the Canadian Council on Social Development using data from Statistics Canada's PALS 2001.

The rate of medication use by children with disabilities increased with age. Among preschoolers with disabilities (that is, those under age 5), 33.8% took some form of medication (prescription or non-prescription) on a regular basis, that is, weekly or more often. Among those aged 5 to 9, 47.7% took medication regularly, and among those aged 10 to 14,

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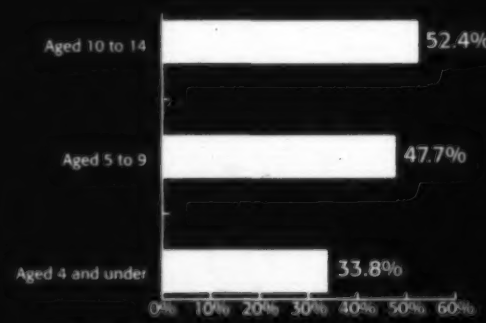
Chart 2 **Regular Medication Use by Children with Disabilities, by Age Group, Canada, 2001**



Note: This includes both prescription and non-prescription medication.
Source: Calculations by the Canadian Council on Social Development using data from Statistics Canada's PALS 2001.

52.4% used medication regularly.[4] The severity of the disability also had an impact on medication use among children with disabilities. As one might expect, as the severity of the disability increases, generally so does the likelihood of taking regular medication. We see this pattern among those aged 5 to 14 with moderate, severe, and very severe disabilities, where 39.3% of those with moderate disabilities took regular medication, compared with 52.3% of those with severe disabilities, and 67.6% of those with very severe disabilities. However, children in this age group who had mild disabilities

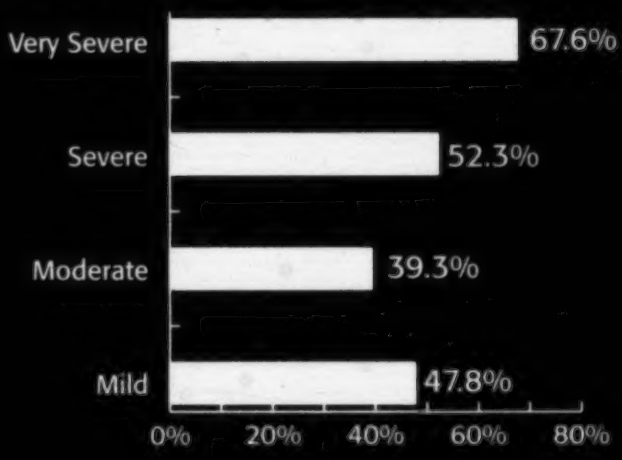
[3] Note: These categories of medication use are not mutually exclusive. Some children may have been taking both prescription and non-prescription medication daily and weekly.

[4] A very large proportion of these rates was due to daily prescription drug use. If we examine *only* the rate of "daily prescription medication" use, we find that 27.8% of preschoolers with disabilities took daily prescription medication, 42% of children with disabilities aged 5 to 9 used prescription medication daily, and among those aged 10 to 14, the rate was 45.3%.

actually had a higher rate of medication use than was found among those with moderate disabilities.

This "dip" in the rate of medication use among children with moderate disabilities is somewhat curious and requires further investigation to determine why this might be so. We hope to return to this in the future.[5] It may be that there are important differences in the nature of the disabilities found; for example, those with moderate disabilities may be more likely to have underlying conditions that do not lend themselves to drug intervention. Perhaps the use of the medication itself helps reduce the severity of the disability.[6]

Chart 3 **Regular Medication Use by Children aged 5 to 14 with Disabilities, by Severity of Disability, Canada, 2001**



Note: This includes both prescription and non-prescription medication. Regular is defined as "at least" weekly, which includes those who take medication daily and/or weekly.
Source: Calculations by the Canadian Council on Social Development using data from Statistics Canada's PALS 2001.

Unmet Need for Medication:

Despite what might seem like a rather high rate of prescription medication use among children, the rate of unmet need was fairly low, at 2.6% of the total population of children with disabilities.[7] That translates into nearly 4,700 children with disabilities who required medication that they did not

[5] Unfortunately, we will be limited by sample size in such an investigation.

[6] Among children under age 5 in the PALS 2001, we are only able to identify two levels of severity: mild to moderate (mild and moderate are combined) and severe to very severe (severe and very severe are combined). We find that 31.7% of children under 5 who had mild to moderate disabilities took regular medication, while 36.6% who had severe to very severe disabilities did so. Both these numbers, however, should be used with caution due to low sample sizes.

[7] This is *not* the percentage of children who "needed" medication and had an unmet need. This is the percentage of *all* children (whether they needed medication or not) who had an unmet need. Information was gathered regarding daily and weekly prescription and non-prescription drug *use*. These are the figures reported in Chart 1. The PALS also contained a question which asked: "Because of a condition or health problem, does ... CURRENTLY need any prescription or non-prescription medications on a regular basis, which he/she does not have?" Those responding "No" to this question may be those who needed medication, but had all they needed, *as well as* those who didn't need or use any medication at all. The PALS also fails to capture information on those using medication less regularly than weekly. For example, those who might have episodic problems requiring medication, where the amount of time between episodes is several weeks or months, were not captured by the PALS.

have.[8] Unfortunately, data concerning the reasons for this unmet need cannot be released due to low sample size restrictions.

Health Care Professionals

Patterns of Use of Health Care Services:

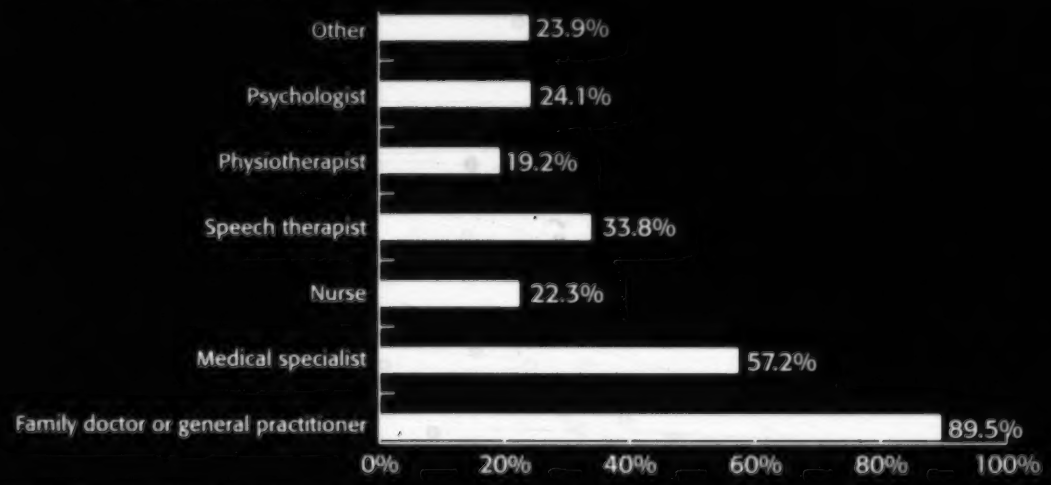
The vast majority of children with disabilities (89.5%) visited a family doctor/general practitioner. As well, 57.2% visited a medical specialist, about one-third (33.8%) visited a speech therapist, and roughly one-quarter visited a psychologist (24.1%), a nurse (22.3%), and "other health care professionals" (23.9%). Nearly one-fifth (19.2%) visited a physiotherapist.[9]

While more children with disabilities had "some" visits to family doctors/general practitioners than to any other type of health care professional, they tended to see family doctors/practitioners less frequently than other types of health care professionals. If we examine the rate of weekly visits to each type of health care professional, speech therapists predominated – with 12.7% of all children with disabilities visiting a speech therapist on a weekly basis and another 9% visiting speech therapists monthly.

[8] In DRIP No. 11, we released data concerning medication use by adults with disabilities. We found that the rate of unmet need among working-age adults was 11.7% for men and 19% for women and among seniors was 3.6% for men and 5.5% for women.

[9] Due to sample size limitations, estimates concerning visits to other health care professionals, such as chiropractors, cannot be released.

Chart 4 **Children under age 15 with Disabilities who Visited Health Professionals, Canada, 2001**



Note: This includes children who visited these professionals weekly, monthly, or less than monthly. Data regarding visits to chiropractors cannot be released due to sample size restrictions.
Source: Calculations by the Canadian Council on Social Development using data from Statistics Canada's PALS 2001.

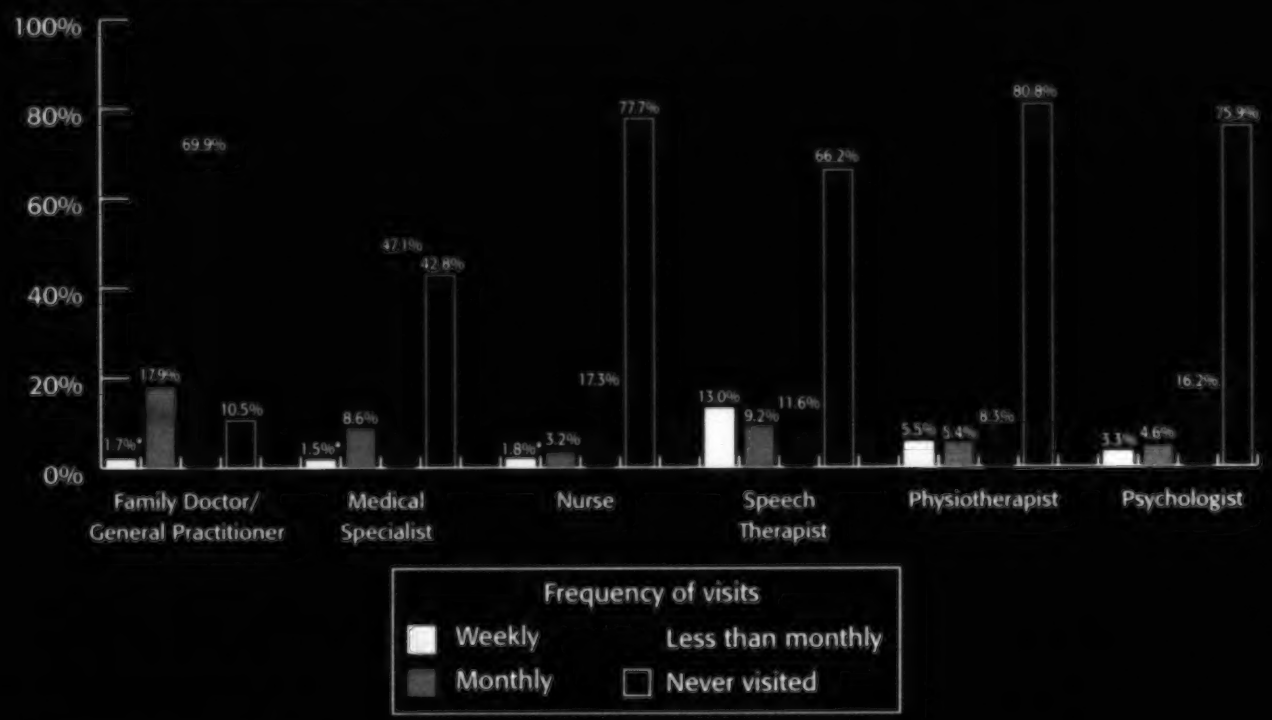
By comparison, less than 2% of all children with disabilities visited family doctors/general practitioners, medical specialists, or nurses on a weekly basis.[10] Physiotherapists and psychologists, although less likely to be visited at all, were quite likely to be visited fairly frequently – 5.4% of children with disabilities saw a physiotherapist on a weekly basis and another 5.3% saw them monthly, while 3.2% saw a psychologist on a weekly basis and another 4.5% on a monthly basis. Family doctors/general practitioners and medical specialists were most likely to be visited at more than monthly intervals: 69.9% for family doctors/general practitioners and 47.1% for medical specialists.

Unmet Need for Health Care Professionals:

When considering demands for various health care professionals, it is important to examine the proportion of children who required *any* form of treatment as well as the *frequency* of those demands. In terms of unmet needs for health care services, 15.5% of children with disabilities had some form of unmet need; speech therapists and "other health care professionals" (not specified) contributed most to this unmet need – 4.9% of all children with disabilities had an unmet need for a speech therapist, and 6.8% had an unmet need for "other health care professionals."

[10] These percentages were all between 1% and 2%; they should be used with caution due to low sample size.

Chart 5 **Frequency of Visits to Health Professionals by Children under age 15 with Disabilities, Canada, 2001**

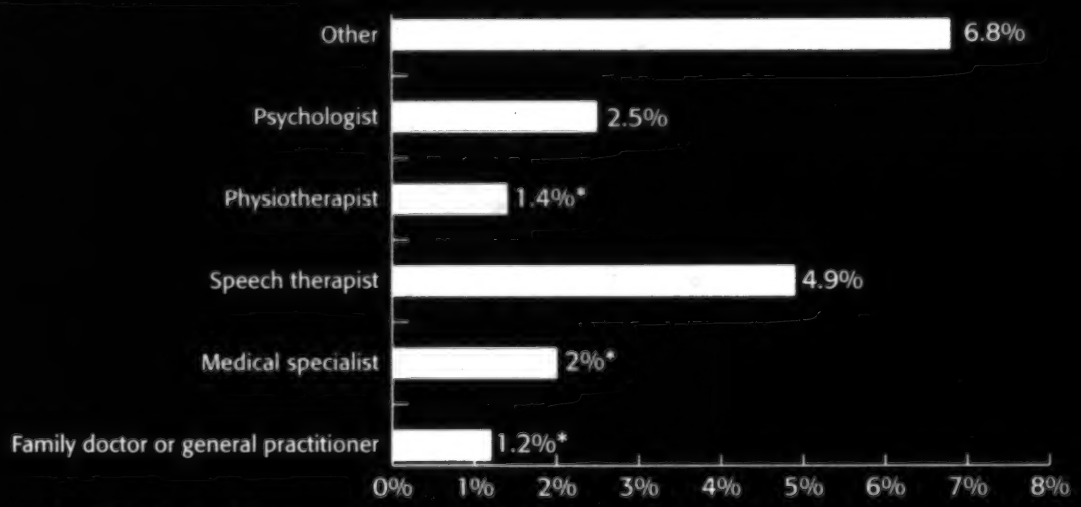


* This estimate should be used with caution due to low sample size.
Source: Calculations by the Canadian Council on Social Development using data from Statistics Canada's PALS 2001.

This difficulty in finding speech therapists for children in Canada has been noted elsewhere as well. For example, in a survey conducted by the Canadian Teachers' Federation in 2000, 38% of Canadian school districts reported having large shortages of speech therapists.[11] In 2001, the CCSD conducted a study of special education involving key informant interviews with a variety of experts in the education field. When asked about the supply of "speech pathologists, occupational therapists, and school psychologists," 100% of the experts said the supply of these professionals was inadequate to meet the demands.[12]

For those with an unmet need for some type of health care professional, "long waiting lists" was the most commonly cited reason, noted by 54.5% of those in need. Economic reasons – lack of insurance coverage was cited by 32.9% and cost cited by 40% – were also commonly reported. Just over one-third (34.1%) reported that the service wasn't available locally. These reasons are also reflected in comments by education experts consulted for the CCSD's 2001 study. Some of those comments included the following:[13]

Chart 6 **Unmet Need for Select Health Professionals among Children under aged 15 with Disabilities, Canada, 2001**



* These estimates should be used with caution due to low sample sizes.
Note: Due to sample size limitations, estimates of unmet need for chiropractors and nurses cannot be released.
Source: Calculations by the Canadian Council on Social Development using data from Statistics Canada's PALS 2001.

[11] The shortages were greatest in French-language districts where "two-thirds of French districts overall reported a 'large' shortage of speech therapists . . . " (page 15, *Economic Services Bulletin*, Teacher Supply and Demand Survey 2000-2005, Canadian Teachers' Federation, 2001). http://www.ctf-fce.ca/en/default.htm?main.htm

[12] Results from this study can be found in three publications by the CCSD: "Special Education in Canada," in *Perception*, Volume 25, No. 2, Fall 2001; *The Progress of Canada's Children 2001*; and *Children and Youth with Special Needs*, by Louise Hanvey. All these reports can be found on the CCSD's website at www.ccsd.ca.

[13] Although these quotes were originally gathered for the 2001 study, they were not previously published.

"Assessments take too long because of the progression of young kids. If you do not assess early, the problem only gets worse. The level of expertise is insufficient. The population base makes it difficult to get health workers and speech pathologists . . . You have to travel to the two cities to receive an assessment and the waiting lists are long; as a result, parents are very frustrated."

"Yes, there is some concern for waiting lists and the amount of wait time for assessments. Access to services such as speech language, physio, and highly specialized services are a problem."

"Some services such as speech/language are waiting 6-8 months to a year. . . It is even worse in rural areas."

Chart 7 **Reasons for Unmet Need for Health Care Professionals among Children under age 15 with Disabilities, Canada, 2001**

Reasons cited for unmet need:	%
Lack of insurance coverage	32.9%
Cost	40.0%
Service not available locally	34.1%
Long waiting period	54.5%
Other	37.6%
Total with an unmet need	100.0%

Note: These percentages apply only to those with an unmet need. Some individuals stated more than one reason.
Source: Calculations by the Canadian Council on Social Development using data from Statistics Canada's PALS 2001.

Coordination of Care by Parents/Guardians

As we have seen, children with disabilities often have high requirements for medication and for the services of health care professionals. For some people, the coordination of this care – making appointments, phoning or visiting health professionals/specialists, and the like – can be complex and time-consuming. For nearly three-quarters of children with disabilities (74.6%), the child's mother was the individual primarily responsible for such coordination.[14] Difficulties coordinating care were experienced by one in five children with disabilities. Of those who had difficulty, "obtaining appointments" was most frequently cited as a problem (noted by 57.1% of those who had difficulty). This is consistent with findings regarding the insufficient supply of certain health care professionals.

Related to this is another "supply-related" factor: 39.2% reported that the needed service was not available locally. Time conflicts also created difficulty for those coordinating care – 50.6% reported that they lacked the time required, and 49.1% reported "work conflicts". Lack of information (35.7%) and lack of communication between health care professionals (36.1%) also led to difficulties in coordinating care. (Note: Since individuals often mentioned more than one problem, there is strong overlap among the reasons cited.)

[14] For 18.2%, both the child's mother and father shared the coordination.

More Research on Children with Disabilities to Come:

Look for additional information on children with disabilities to be published in the CCSD's report, *The Progress of Canada's Children 2005*, scheduled for release in the Fall. Information will be provided on a variety of aspects of the lives of Canadian children with disabilities, with a particular focus on their school experiences. For example, we will examine more closely the one-third of school-aged children with disabilities in Canada who had difficulty accessing special education in 2001.

A Final Note on CCSD's Disability Research Information Sheets:

With this issue, the current funding for the CCSD's *Disability Research Information Sheets* has come to an end. And while we hope to obtain funding to continue producing these *Information Sheets*, the future of this project is uncertain. We would like to take this opportunity to thank our readers for their continued support and thank the many individuals who have provided valuable feedback, comments, and information requests over the last five years. Regardless of whether the *Information Sheets* resume, however, please continue to check the CCSD's website for other projects in the area of disability research (www.ccsd.ca/drip/index.htm).

Important Message

The Office for Disability Issues at Social Development Canada would like to invite you to participate in an electronic survey evaluating the impact of the CCSD's *Disability Research Information Sheets* (DRIP) and how well they respond to your information needs.

You can make an important contribution to this project review by taking a few minutes to complete the online questionnaire (at www.ggi.nf.ca/dripsurvey) and share your opinions on the DRIP. Results of the survey will be compiled by an independent firm on behalf of Social Development Canada.

We look forward to your input and thank you for your collaboration.

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